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Projects and Developments

Special issue: Infrastructures to support integrated care: connecting across institutional and professional boundaries -

Challenges for IT-supported shared care: a qualitative analyses of two shared care initiatives for diabetes treatment in Denmark

"I'll never use it" (GP5).

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Abstract

Purpose: To investigate the circumstances as to *why it is so difficult in the primary care sector to implement IT based infrastructures supporting shared care.*

Case study: The qualitative analysis includes two separate case studies of IT-supported shared care implemented in two different regions of Denmark throughout 2005. The study comprises 21 interviews and 35 hours of observations. The data were analysed through a coding process that led to the emergence of three main challenges impeding the organisational implementation of IT-supported shared care.

Discussion and conclusion: The two cases faced the same challenges that led to the same problem: The secondary care sector quickly adopted the system while the primary sector was far more sceptical towards using it. In both cases, we observe a discrepancy of needs satisfied, especially with regard to the primary care sector and its general practitioners which hinder bridging the primary sector (general practitioners) and the secondary sector (hospitals and outpatient clinics). Especially the needs associated with the primary sector were not being satisfied. We discovered three main challenges related to bridging the gap between the two sectors: (1) Poor integration with the general practitioners' existing IT systems; (2) low compatibility with general practitioners' work ethic; (3) and discrepancy between the number of diabetes patients and the related need for shared care. We conclude that development of IT-supported shared care must recognise the underlying and significant differences between the primary and secondary care sectors: If IT-supported shared care does not meet the needs of the general practitioners as well as the needs of the secondary care sector the initiative will fail.

Keywords

shared care, IT-support, challenges, diabetes, organisational implementation, primary care sector, secondary care sector, qualitative case study

Introduction

During the past decade in Denmark, electronic information technologies (IT), representing infrastructures that support integrated and long-term medical care across hospitals and professional boundaries, have

been the subject of extensive investments and multiple implementation efforts. Recently, a greater interest and focus have evolved around bridging not only institutional and professional boundaries within the secondary care sector (hospitals and outpatient clinics) but also between the secondary and primary care

sector (represented by general practitioners). Such initiatives for integrated care are labelled under the banner of supporting 'shared care' [1]: establishing coherent treatment of the patient through close co-ordination and cooperation across care sector boundaries. The recent initiatives in establishing technological infrastructures to support shared care have experienced new and unforeseen challenges that are rooted in the different natures of the two sectors. This article describes two recent initiatives in Denmark that aim at supporting shared care for diabetes treatment. This article also identifies some major challenges for the development and organisational implementation of shared care systems.

The two shared care initiatives took place during 2005 in two different regions of Denmark. There are a total of five regions in all in Denmark. Both cases focus on the treatment of diabetes. Though there were differences between the two cases' development strategies, both cases faced the same problem: The secondary care sector quickly adopted the system while the primary sector was far more sceptical in using the system. In both cases similar challenges that lead to a rejection of the system by the primary sector and – hence – to a failure of the shared care initiatives as such, can be identified.

In this article we investigate the circumstances of the two shared care *initiatives and identify the main challenges constraining the development of technological infrastructures supporting shared care in the primary care sector*. There is very little qualitative research exploring the practical barriers to the adoption of such systems in the primary care sector [2]. Based on qualitative and comparative analyses of both cases, we identify and elaborate on three major challenges and conclude that the common denominator present in both initiatives has been the diabetes treatment seen from the perspective of the secondary sector, as opposed to the perspective of the general practitioner.

In the following, related work as well as our research method is presented. We then briefly introduce diabetes, diabetes treatment, and the shared care policy in Denmark. This is followed by the main part of the article describing the two case studies. First, these studies are introduced and the development process for each case is presented. Then the three challenges constraining the development of the shared care infrastructure are unfolded: (1) Poor integration of the shared care systems; (2) low compatibility with general practitioners' work ethic; (3) and discrepancy between the number of diabetes patients and the related need for shared care. Finally, a conclusion is drawn.

Related work

Shared care initiatives in general are expected not only to improve communication and coordination [1], in particular through electronic referral and discharge letters [3], but also to provide higher quality and efficiency by bridging the health sector divide [4] and thereby offer more coherent health services [5].

Earlier studies of integrated care across sector boundaries can be divided into three groups: Studies concerning data *exchange*; studies dealing with the *integration* of data (on condition of data exchange); and studies concerning *shared* or *integrated care* (on condition of data integration). Most studies use a quantitative research approach. Studies related to the first two groups typically focus on the technical problems with and possibilities for data exchange and integration. This includes investigating exchange standards, such as the Electronic Data Interchange For Administration, Commerce, and Transport (EDIFACT) [6] and the Clinical Document Architecture (CDA) [7,8]. Or it includes addressing security issues regarding data storage and access rights [9–11] e.g. by means of smart cards [4,12,13]. Exchanging and integrating data are a prerequisite for supporting shared care [9,10] *shared care is more than just sharing data*. Hickman et al. define shared care as "the joint participation of general practitioners and hospital consultants in the planning and delivery of care for patients with a chronic condition, informed by an enhanced information exchange over and above routine discharge and referral letters" [14:447–8]. In our study the aim of both initiatives were to support shared or integrated care. The IT systems ended up though supporting primarily data exchange and data integration.

An example of a study dealing with data exchange and integration is Branger et al. [6], who studied the replacement of paper-based records with Electronic Data Interchange (EDI) between primary and secondary care. The EDI messages could be integrated into the medical record by choosing where to integrate each data from the EDI message into the medical record. Branger et al. found a higher frequency of communication and found that 75% of the EDI data was integrated. A follow up study on Branger et al.'s study showed that the volume of electronic messages remained the same but there was a decrease in integrating the messages into the respective fields in their medical record. One explanation for this was that the messages decreased the overview of the record [15]. Müller et al. [7] investigated how the CDA standard can be used to exchange data between hospitals and general practitioners. They found CDA

to be a promising method for enhanced electronic data exchange, though they also found that there still were issues to be resolved such as technical infrastructure and organisational frameworks.

The analysis of the Danish initiatives in this article focuses on the development of technologically supported infrastructural arrangements, i.e. the organisational implementation of IT-supported shared or integrated care [16]. Both initiatives were aiming at supporting collaboration and joint participation in the treatment of the patient by means of using a shared IT system and by *sharing* clinical data recorded by the general practitioner as well as by clinical staff at the outpatient clinics.

A number of reviews and investigations have found positive effects on patient care due to increased cross-section collaboration [3,17,18]. Most of the studies that revolve around investigating infrastructural arrangements that support integrated care in diabetes (with or without IT), focus on the medical outcome for the patients. None of them have provided evidence of the effect of integrated care [5,18]. Smith et al. [19,20] found significant improvements in diabetes care delivery, but no improvements in the biomedical outcome. Naji [21] evaluated the effectiveness and efficiency of IT-supported shared care for diabetes patients and found that the IT-supported shared care was at least as effective as conventional hospital clinic care. Naji [21] gives the possible explanation that the general practitioners involved in the experiment were particularly interested in the treatment of diabetes.

In the literature concerning shared care and integrated care we have not found any studies concerning the users role in adopting technological infrastructures supporting shared care. Short et al. [2] have conducted a qualitative study of the general practitioners' barriers to the adoption of an IT system that supports decisions made during their consultations. They identify challenges that correspond to the challenges that we find with relation to the adoption of IT-supported shared care. Short et al. [2] identify constraining challenges such as 'time pressure' (it can be hard to find time to incorporate using yet another new IT system in a 10 minute consultation); 'infrequent use'; and for some of the general practitioners, 'limited skills and confidence in IT' was also an issue.

Case study

The two cases presented in this article have been analysed by means of qualitative research methods [22]. The empirical work took place throughout 2005 and comprises 4 interviews with physicians and 2

interviews with nurses (from the outpatients clinics); 7 interviews with general practitioners; 3 interviews with developers from the IT-companies (one with a project manager from company-1 and 2 interviews with two different project managers from company-2) and another 2 interviews with representatives from each of the two regions (the developer companies are in the following referred to as company-1 and company-2). The interviews were semi-structured and lasted around 45–75 minutes. Most interviews were recorded and later transcribed. The interviews were supplemented by 35 hours of observation, where the use of the systems on the outpatients clinics was observed. Additional time was spent observing the general practitioners in their daily work when only using their own medical record system. We also observed introduction courses of the systems from both cases and conducted document analyses of a number of relevant documents, including requirement specifications, information material, user manuals, etc.

Interview transcripts and other field notes from the interviews and observations were analysed using a coding process inspired by the theoretic sampling technique known from grounded theory [22,23]. The empirical material was coded into categories through a repeating process of comparison and evaluation. The content of the interviews was organised as interesting and meaningful statements. These were grouped and categorised by designating the classifications into low level categories [23, pp. 45ff]. Examples of the categories were: Purpose of the shared care systems; use of the computer; organisational implementation; work flows; and communication across sectors. The categories were then grouped into themes identifying the challenges.

An example on a statement from the 'purpose of the shared care systems' category, which shows the imbalance in the need for shared care, follows here:

From my point of view, system 2 is made by people who don't think we do anything else but treat diabetes patients and, therefore, have one hour for each patient (GP4).

Another example from 'communication across sectors' that shows that the communication works fine for the general practitioner and that there is no need for such a system, follows here:

It is not always them [the doctors at the outpatients clinic] that mention the cholesterol numbers, but I get them when they send me the letter of discharge. So I don't need to go into a database to see it (GP6).

This quote also indicates that the system does not provide the general practitioner with other information

than he already gets in the present organisation from the referral and discharge letters.

The data from the two cases were analysed separately and later compared. The results were combined with document analysis and three succeeding interviews with the developers and representatives from the two areas. Our findings have been reported on and on several occasions discussed with management, clinicians, and other informants from the cases.

Diabetes

Diabetes is a rapidly growing (epidemic) chronic disease. In Denmark (with approximately 5 million inhabitants), the number of diabetics is estimated to be about 2–300,000 and this number is rising with 10–20,000 each year. People with diabetes have a problem controlling their blood sugar either because of insulin resistance (type 2 diabetes) or a lack of insulin production (type 1 diabetes). The aim of the patients is to keep their level of blood sugar as stable as possible, which can be controlled through a healthy diet and exercise together with proper medication. Diabetes results in an increased risk of a number of complications such as cardiovascular diseases, arteriosclerosis, reduced sight, etc. These complications can be postponed or avoided with an appropriate regulation of the patient's blood sugar.

In Denmark, people with diabetes are most of the time treated by their general practitioner, which typically means that they have to attend a regular consultation with their general practitioner every three months and attend a more thorough check-up once a year. The general practitioner functions as a gatekeeper between the primary and the secondary care sector, and the vast majority of diabetic patients enter the health care system by means of consulting their general practitioner. When a patient consults the general practitioner, the general practitioner evaluates the need for referring the patient to the secondary sector, which in Denmark and in the case of diabetes, is an outpatient clinic. Outpatient clinics are located at the hospital as part of the diabetes medical ward. The staff at the clinic includes diabetologists, endocrinologists, chiropodists, dieticians, and diabetes nurses. Diabetes patients are for the most part treated solely by their general practitioner. If complications arise, such as unstable blood sugar or severe non compliance, the patient is referred to the outpatient clinic. The outpatient clinic will normally continue to see the patient every three months for a period of 1–2 years or until the patient's condition is stabilised. When this has happened the patient is referred back to the

general practitioner who then takes over from here. Only a few patients are treated solely by the outpatient clinic, and they typically represent severe cases of type 1 diabetes.

Shared care

Shared or integrated care denotes care where “the patient is shared between individuals or teams who are part of separate organisations or where substantial organisational boundaries exist” [1, p. 8]. The application area for shared care has typically been related to chronic diseases – as for example diabetes. Shared care is in this respect defined as “the joint participation of general practitioners and hospital consultants in the planned delivery of care for patients with a chronic condition” [14, pp. 447f]. Initiatives in order to IT-support shared care with regard to diabetes patients have recently been taken in Denmark [16,18,24,25] as well as abroad [20,26–28].

Shared care, and IT-supported shared care, are generally articulated as positive and necessary in order to improve coordination and cooperation across care sector boundaries:

Shared care is one approach to improving care at the interface [between the primary and secondary care sector] by minimising the apparent fragmentation of service [5, p. 34].

In Denmark, IT-supported shared care is articulated as a general solution to the increasing problem of chronic diseases [29]. IT-supported shared care is a central part of the national IT strategy [30]. It is an area of action with regards to the current health reform in Denmark [31]. It is part of the action plan with regards to the national initiatives concerning diabetes [32–34]. It also has high priority with regards to national quality assurance initiatives [35,36]. The Association of County Councils (now referred to as the Danish Regions), which is responsible for the secondary care sector, anticipates great improvements in the health care sector due to the future development of technological infrastructures by means of IT-supported shared [37–39]:

The general practitioners are complaining that they do not know what we [the secondary care sector] tell the patients. If they could get access to the patient records they would always be able to see what happens [38, p. 27].

Shared care as the ‘solution’ to chronic diseases is also articulated within the community of physicians and general practitioners:

Figure 1. Screen dump System -1.

The road to raise the quality of patient trajectories in Danish hospitals is through an increased coordination, continuity, communication, and interdisciplinarity [40:1560].

By all means the so-called shared care between general practitioners and hospitals seems to be the way forward for many patients with serious chronic diseases [25:322].

Shared care has become a positive value-laden 'buzzword', a commonly referred to means for achieving an improvement, and a label denoting a number of different strategies, action plans, and initiatives. In this article, the main actors of the analysis are representatives from the primary and secondary care sector. However, a key actor influencing the stress towards initiating the development of technological infrastructures in terms of IT-supported shared care, is a grey eminence in the form of various national institutions such as the Ministry of Health, National Board of Health, and others, who establish and articulate the political pressure for action through national strategies, action plans, etc. [30–39].

The two cases

We have investigated two different cases of shared care initiatives (in the following referred to as case-1 and case-2), both of which took place in two geographically different regions in Denmark (which we refer to as area-1 and area-2). The cases involved two different web-based IT systems specifically aiming at supporting shared care (system-1 and system-2, respectively).

Case-1 concerns a system that originally was developed during the period 1992–94 by a biochemist and a chief physician at the largest outpatient clinic in area-1. In the beginning it was only meant to record 'hardcore' biochemical data relevant to diabetes, such as blood sugar levels, etc. Later in 1997 an endocrinologist came to the outpatient clinic and took part in the development, and at the same time a young student of informatics was also drawn into the project. The latter started an IT company on the basis of porting system-1 to a web-based system [41]. In 2000 the old version of system-1 was replaced by this web-based version of system-1 at the outpatient clinic, and the aim was to implement it in all outpatient clinics throughout area-1. In 2004, a steering committee was established with representatives from the central IT-unit (a unit responsibility for the secondary care sector within area-1), with representatives from the IT company, and three representatives that were general practitioners. They all had the task of developing and promoting a 'light' version of system-1 specifically intended for the general practitioner. 'Light' means that the system basically was identical to system-1 used by the outpatient clinics but with reduced functionality. A requirement specification for the light version of system-1 was devised and in 2005 the first light version was ready to be tested [see Figure 1].

The test, however, revealed unsatisfactory results and the roll-out to the general practitioners was postponed indefinitely. In 2006 however, the system was modified according to some of the test results and the roll-out plan was re-established. In 2006 system-1 was accepted by all of area-1's outpatient clinics. Some



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Status			
Kontakt	Insulin	DNA	Alder
240306 Rutinekontrol Lukket	Humulin Regular 53 IU/dag 160404	Biguanid Orabet 500 mg 2*2 051203	53 år
160404 Rutinekontrol M OUH			
051203 Rutinekontrol M OUH			
050903 Rutinekontrol M OUH			
Højde	Anden behandling	Egenskaber	Ryger
Højde 150 cm 050105	For hypertension cozaar 50 mg 1*1 051203	Ryger 20 cig/dag 181105	Ryger indtil 15 timer/uge 181105
Vægt 78,6 kg 051203	For hypertension norvasc 5 mg * 1 051203		
BMI 34,93 kg/m² 051203	For dyslipidemi zarator 10 mg 041203		
BT 120/75 mmHg 051203	For hypertension centyl m kcl 1*1 041203		
Laboratorieresultater	Patienthistorik	Akutte komplikationer	Andre komplikationer
HbA1c 0,07900 050404	BHY1 Til næste gang UAL ... 160404	Svær hypoglykæmi X	Angina X
nU-albumin 1,000 mg/mmol 210203		Ketoacidose X	Claudication X
S-kreatinin 84,000 µmol/l 210203		AMI X	Terminal nyreinsufficiens X
Kreatininclearance 4,2 mmol/l 050404		Apopleksi X	Inj. Infiltrater X
S-kolesterol 2,2 mmol/l 050404			
S-HDL-kolesterol 1,51 mmol/l 050404			
S-triglycerid 0,99 mmol/l 050404			
GAD			
C-peptid			

Figure 2. Screen dump System -2.

outpatient clinics are still in the process of implementing system-1 but the majority of outpatient clinics now routinely use the system. System-1 is, however, still not in use by any of the general practitioners. From October 2006 until March 2007, system-1 has been tested but only 3 out of 10 general practitioners have managed to use the system during the test period due to technical problems. So there is yet no real valid result from the use of system-1 on the part of the general practitioners.

In case-2 the initiative for the new system was taken by the county diabetic committee in area-2 consisting of representatives from the management level at the hospitals and at related outpatient clinics dealing with diabetes in area-2, three so-called Diabetes Practice Consultants (described further below), as well as patients with diabetes. There was no existing system (as in case-1), rather the starting point was finding an answer to the demands for shared care initiatives given by the National Board of Health, as pointed out above. The diabetic committee contacted a large IT-company, that for some time had been developing a new IT system (system-2) supporting the treatment of diabetes, and they then started collaborating. It was decided early on that system-2, which is intended to be sold both nationally and internationally, should be web-based and use the same data in both the primary and secondary care sectors to promote information exchange [see Figure 2].

System-2 was also meant to be used during the actual consultation (and not e.g. after the consultation), to avoid double registration of data and to support the involvement of the patient.

The implementation at area-2's outpatient clinics started in spring 2003 and within a few months, system-2 was used by all the outpatient clinics in that

area. The introduction of system-2 to the general practitioners began in 2004 and was accompanied by a comprehensive effort to encourage the general practitioners in using the system. All general practitioners were invited to a half-day introduction course which was mandatory for getting a password to system-2. A year later more than 80% of the area's general practitioners had participated in the course. The general practitioners were also assured a special bonus when reporting the results from the patients' yearly control with system-2. In 2006 most general practitioners in the area had access to system-2 but only a few used it. A survey made by the committee in 2006 found that only about 15% of the general practitioners used system-2 on a regular basis. At the end of 2006 the number of regular users among the general practitioners was about 30% of those who had been registered as users¹. So even though system-2 was rapidly adopted by the outpatient clinics, less than 25% of the general practitioners had adopted the system two years after the intensive introduction.

The development processes

The development processes of the infrastructural arrangements in both cases differ in some respect but also share some decisive similarities.

The cases differ with respect to the overall development approach, which in case-1 can be characterised as bottom-up and in case-2 as top-down. In case-1 the initiative for system-1 (both in its original version

¹ Regular users include already registered users who have logged into the system one or more times during one week. This means that only general practitioners that have been registered and have a password count as users. General practitioners who have not attended an introduction course which is a precondition to get registered, are not in the statistics. 5–10% of the GPs still need to register.

as well as in the light version offered to the general practitioners) came from the end-users, in terms of the outpatient clinics' chief physicians. Chief physicians from the involved outpatient clinics independently established a steering committee and managed the development process with a relatively small budget during a multi-annual period involving different versions of system-1 [41,42]. The development process in case-2 arose from a top-down approach with a central committee established by the management of the secondary care sector [43]. The development process was relatively short, aiming at system-2 in its current version. The budget was tenfold larger than in case-1 and included funding from the pharmaceutical industry.

Both cases share, however, a more determining characteristic of the development approach from the secondary sector to the primary sector. This can be phrased as 'inside-out': inside, from the hospitals and their outpatient clinics seen as the core of the care sector, and out, to the general practitioners seen as satellites surrounding the care sector. We can identify three conditions that have contributed to the circumstances resulting in this inside-out approach: *Firstly*, the articulation of the overall need for IT-supported shared care from a national level, including the ministry of health and national board of health, is primarily placing pressure on the secondary sector in order to take action. *Secondly*, the organisational structure of the secondary care sector simplifies the management of the development process. The secondary sector is organised as a traditional hierarchical bureaucracy. Management can decide that hospitals and outpatient clinics in their area must adopt and use the system. General practitioners constitute a much looser form of network of independently run private practices. General practitioners can be motivated to accept the system but there is no formal authority that can decide that they *must* do it. The development process can thus in the secondary sector be characterised as a "primary authority innovation-decision process" and in the primary sector as a "collective and optional innovation-decision process" [44]. Collective because the purpose of the system will be lost if not the majority of the general practitioners accept the system. *Thirdly*, the manner in which general practitioners are organised, with regard to diabetes issues, promotes the secondary sector's interests and needs. In order to support the collaboration between the primary and secondary care sectors in Denmark, a number of general practitioners participate in a network of Practice Consultants² [45]. Among these, some are

² Nationwide there are more than 300 practice consultants covering almost all medical specialties. A practice consultant is hired on an hourly basis working from 5 to 30 hours a month on improving the cooperation between the general practitioners and the hospitals, e.g. establishing common treatment guidelines.

appointed the function of diabetes practice consultants: They have a special interest in and knowledge about diabetes; they are paid a special fee for participating in the network; their responsibility with regards to further the overall integration of diabetes care entails an epidemiological interest closely related to their colleagues at the outpatient clinics. The diabetes practice consultants thus represent a perspective that might reflect the secondary sector rather than the primary sector. But the diabetes practice consultants also represent an expert group of the general practitioners (who otherwise do not have any organised representation), which becomes especially important when facing diabetes related initiatives from the secondary sector. In both cases the diabetes practice consultants were chosen to be members of the steering committees, and thus making them primary informants for the developing IT companies when testing the systems.

In case-2 the practice consultant was not viewed as a "true" representative for the general practitioners but a representative from the county due to his strong involvement and association with the steering committee.

I don't know how many who use it [the system] as such. That uses it daily to everything. That they [the people behind the system] don't want to tell. When I talk to him [the practice consultant] he says that there are many but how many he won't tell. (GP6).

The inside-out approach has implied that the development processes in both cases are grounded in the secondary care sector and, therefore, the focus has been primarily on the secondary care sector's interests, wishes, and demands.

Challenges for IT-supported shared care

In the two cases, we can observe a discrepancy of needs satisfied, especially with regard to the primary care sector and its general practitioners. Even though case-1 can be characterised as bottom-up and case-2 as top-down, both cases share an inside-out approach due to the fact that both initiatives originated from the outpatient clinics and the primary sector was involved afterwards. This implied that the general practitioners did not obtain an equal amount of influence on the development processes. The results were threefold in both cases. First, the shared care systems were weakly integrated with the general practitioners' existing IT systems. Secondly, using the system in some ways contradicts the general practitioners' work ethic in terms of values and views on patients that can in

turn influence their work practices. Lastly, the shared care solutions do not recognise the varying number of diabetes patients at the outpatient clinics (many diabetes patients and only diabetes patients) and at the general practitioners (few diabetes patients among many other patients). These three results that challenged the development of IT-supported shared care are described in more detail below.

Poor integration with the general practitioners' existing IT systems

Virtually all Danish general practitioners use IT to record their clinical notes in electronic patient records and to send and receive clinical electronic messages [46,47]. There are in total 19 different electronic patient record systems available on the Danish market. The general practitioner's investment in his electronic patient record system is considerable: He has to finance the investment out of his own budget; the vendor typically offers only a short introduction to the system, leaving the general practitioner responsible for the majority of tasks involved in implementing the system and integrating it with the work organisation and work practices in his clinic. His electronic patient record system constitutes a very important tool for his clinic as *the* single documentation tool in use. The general practitioner's investment, considerations, and work involved bring about a kind of devotion to the system that might be compared to that of the taxi driver and his car.

The general practitioners were in favour of an integrated solution and they were in general concerned with the prospect of having yet another new IT system for each shared care initiative that might be made for each chronic disease. They suggested developing a shared care system that would use the data recorded in their electronic patient record systems:

I was quite insisting on this matter, but it was technically not possible to do this at this point in time. I am of the opinion that a [shared care system] should have been developed where the application should be within our computers (GP6).

If it [shared care system] was on my computer then it could get most of the data [from my electronic patient record system]. But there should be a little piece of code that did this [automatically] (GP7).

It has to ease our workday. It should not be something that we have to spend extra time on (GP3).

In both cases, however, it was noted that integrating a shared care system with 19 different electronic patient record systems, and thus maintaining such an integration along with new updates and versions of each of these 19 systems, would be insurmountable

as well as very costly. The result was, therefore, a decision to develop web-based shared care systems, which were to be used as independent systems in addition to the general practitioners' existing patient record systems. In order to meet the general practitioners' concerns regarding having to record data twice, both in the shared care system as well as in their patient record system, some integration was considered in both cases. Data recorded in the shared care systems are returned to the general practitioner as an EDIFACT. This EDIFACT can then be imported by the patient record systems. With this type of low-tech integration it is claimed that no data have to be recorded twice due to the shared care systems. In principle this is true, but the solution is a poor one, as seen from the general practitioner's view: The EDIFACT message is stored in the general practitioner's system as a special note for the patient in question. This means that the data are added to the patient record as an unstructured text note. Since the data will not be an integral part of the system's structured patient record database, it might easily become problematic to maintain a general view of the patient record. This observation correlates with the study by Branger et al. [6], reported on above in the section on Related Work. In order to meet this problem in case-1, a guide was made instructing the general practitioner on how to write programme scripts in order to convert EDIFACT messages from the shared care system to data records in the patient record system. At the time this study was completed, the EDIFACT solution and associated guide only covered 6 of the 19 systems, and we have not been able to identify any general practitioner that has overcome this immense and tedious task. If one wants to oblige both the needs of the primary and secondary sector the integration could have been done more smoothly though it could end up being very costly.

To sum up, a technical challenge was solved by giving up developing a solution that would integrate the shared care systems with the general practitioners' 19 different electronic patient systems. Instead, a web-based system was developed where the general practitioner had to use it along with his own patient system. Data integration by means of EDIFACT was never really taken seriously, which left it up to the general practitioner himself to programme this integration. The result is a shared care system that is not integrated with the general practitioner's own patient system and which results in redundant data recording and a lack of information overview with regards to the diabetes patient he is consulting.

Low compatibility with the general practitioners' work ethic

The general practitioners' work ethic, in terms of their perspectives on patients and their interaction with patients, influence their work practices. We see their work ethic as underlying their work practices.

The shared care systems in both cases were developed as real-time systems to be used during the consultation with the patient and to support the workflow of this consultation. Our observations show that the systems were used in this way in the outpatient clinics. The shared care systems constitute the outpatient clinic's most important system and since all their patients are diabetics the clinicians used it in a routine manner as the primary tool supporting the consultation. In an outpatient clinic in area-2, the physician turned the screen so the patient could see it and used the system throughout the consultation referring to figures, etc., appearing on the screen. In an outpatient clinic in area-1 a nurse was operating the system during the physician's consultation with the patient.

None of the general practitioners expressed a wish to use the shared care system in a similar manner. On the contrary, they said they prefer using the system after the patient has left in order to be physically and mentally present during the consultation, not to mention the lack of time as well during the consultation. Only a relatively few of the general practitioners' patients are diabetics and the primary tool is the practitioners patient record system. This is usually used infrequently during the consultation for ad-hoc queries and recordings. General practitioners generally regard the time communicating face-to-face with the patient as the most important quality of the consultation [48]. The concept of 'quality-time' during the consultation (face-to-face communication) was brought up several times during our interviews with the general practitioners, and many general practitioners are reluctant to use the computer at all during the consultation.

I would rather use the time—and I might sound a little self-righteous now—but I prefer using my time with the patient and then use the computer either before or after [the consultation]. That's what I do generally (GP5).

I won't sit with my back to the patient [facing the computer]. I believe that's rude ... it is not the job of a physician to sit and act like a computer nerd (GP4).

GP: I have to obtain maximum presence. Interviewer: So using a system like this [shared care system]...

GP: Then I would kind of disappear ... the patient would feel that ... "Hey—doctor, it's me that's ill...

doctor, I am sitting over here ... shouldn't you look in my throat?". It [the shared care system] does not comply with my way of being a doctor (GP4).

Even when the general practitioner experiences that the shared care system could give support during the consultation he is still reluctant to use it:

Most often I wait until the patient has left [the consultation]. Then I have recorded it [the data during the consultation] on a little piece of paper. It is a little annoying when sometimes I do not remember to write everything down [which becomes apparent when using the shared care system after the consultation]. But that's the cost of doing it my way (GP5).

It seems like it contradicts with the general practitioners' work ethic to use the computer as an integrated part of his consultation with the patient. He would rather use the computer as a tool before, at the end, or after the consultation. It is a challenge requiring the general practitioner to use the shared care system and do the accompanying extra work as part of the consultation – as the system is intended for – in order to support the treatment procedure. Changing the general practitioners' work ethic, as part of making them adopt the shared care system and workflow as intended, might be a protracted process [44].

Discrepancy between the number of diabetes patients and the related need for shared care

There is a conspicuous difference in the number of diabetes patients treated and the related need for IT-supported share care with regards to the outpatient clinics and the general practitioners, respectively.

The outpatient clinics only treat diabetes patients. A patient must be referred to the outpatient clinic by the general practitioner and the outpatient clinic's initial information about the patient thus stems from this referral. The outpatient clinic's physicians are experts in diabetes, and epidemiology and research obligations are part of their responsibility and daily work. With regards to research, monitoring diabetes from an epidemiological perspective, and as means to improve the overall quality of diabetes treatment, the outpatient clinics have a strong interest in systematic and thorough data recordings. The outpatient clinics are willing to invest time and resources in achieving a more elaborated data recording. In order to have more accurate recordings of the number of diagnosed diabetes patients, and in turn how the chronic disorder develops, it requires in general that data are captured regularly by the general practitioners. It also requires

the general practitioner to record data beyond the observations, values, and deviations that he has to consider making an intervention upon.

Here in the general practises we are very busy so we cannot record everything that's normal. We document the discrepancies. But at the hospitals they use "tons of time" documenting everything that's normal—because they have to do that. And they don't have to think about how much time the secretaries use, they can talk and talk for hours. And then everything is documented. We do not have the staff for doing that. It is the discrepancies and the important issues [that we record]. And then of course the medicine (GP4).

To the general practitioner, diabetes patients only constitute a minor part of their overall number of patients. Only one out of 20 patients meeting the general practitioner suffers from diabetes [47]. The general practitioners interviewed had between 10 and 60 diabetes patients, out of which only 1–15 are referred to an outpatient clinic. Usually the general practitioner manages to keep his diabetes patients well regulated. Thus, the general practitioner rarely makes a referral to the outpatient clinic. General practitioners do not experience mutual dependencies or needs for increased cooperation requiring special IT-supported shared care with the outpatient clinics.

I would say that shared care with regards to diabetes: There is not much 'shared' in this because if they are referred to an outpatient clinic then they take care of them and then you [the general practitioner] should not interfere with this (GP6).

Either I take care of my diabetes patients or the outpatient clinic does. [Most often] I manage them myself and then there are some cases where they are hard to manage. They are then referred to the outpatient clinic and they will take care of the big annual check-up (GP4).

The low number of diabetes patients and even lower number of referrals to the outpatient clinics, seen from the general practitioner's point of view, entails that he does not experience any particular need for a shared care system. On the contrary, the general practitioner is generally dependent on using his own patient record system. Being satisfied with his patient record system and not seeing any particular benefits from using the shared care system seriously challenges convincing the general practitioner on spending resources and time on this solution [49]. Some of the general practitioners expressed a wish for extended functionality in their patient record system supporting diabetes treatment. For example they wished the system was capable of drawing list of patients with certain characteristics to be able to localize those with high blood pressure or blood sugar and then compare the values

of their patients with the values of other doctors' patients to monitor their quality and level of treatment. But the wish was more of a "nice to have" than a "need to have" wish and some of the needs would nonetheless (according to the developers) not be fulfilled with the shared care system.

In summary, there are very different needs for shared care support in the secondary and primary sector and the difference is revealed by the varying number of diabetes patients treated: The outpatient clinics are a kind of 'factory' treating many diabetes patients (and only diabetes patients). They are specialised in diabetes and their obligations with regard to research and epidemiological monitoring encourage systematic, thorough, and sustained data recordings. The general practitioners treat relatively few diabetes patients. Their obligation is a 'general' treatment where discrepancies from the norms are in focus. Only few of the general practitioners' diabetes patients are subject to a referral to the outpatient clinic and the general practitioners did not experience any special needs for increased cooperation as part the referral.

Conclusion

The two cases presented in this article represent some of the first serious initiatives for IT-supported shared care for diabetes treatment in Denmark. The cases are different with regards to the development processes: Case-1 has a year long history with several versions of system-1, a system developed bottom-up and managed by the chief physicians from the involved outpatient clinics. Case-2 represents a more prestigious large scale effort initiated and managed top-down and involving large funding and a multinational IT company. However, we observe that both cases result in an inside-out approach, where the initiatives for developing infrastructures originate from the secondary care sector: The result is a primary focus on the secondary care sector's interests, needs, and demands. This is partly due to the national articulation justifying IT-supported shared care as an aim in itself and partly due to the inherent problems of representing the general practitioners.

Both cases resulted in a situation where the secondary care sector quickly adopted the system while the primary sector was far more sceptical towards using it. Why it is so difficult to implement IT based infrastructures supporting shared care in the primary care sector? Our study has identified three relevant challenges that contribute to the answer to this question:

- Shared care solutions need to be integrated with the general practitioners' existing IT systems—otherwise the general practitioner is confronted with

redundant data recording and will experience a lack of information overview with regards to the diabetes patient he is consulting.

- Shared care solutions should recognize that both the work practice and the work ethic differ within the primary and secondary sector. A workflow embedded in a shared care system might work fine as an integral part of the consultation in the secondary sector and at the same time it might contradict with the general practitioner's routine and treatment procedure.
- Shared care solutions must take into account the discrepancy between the number of treated diabetes patients and the related need for shared care within the two sectors. The secondary sector's specialisation and related need for systematic, thorough, and sustained data recordings does not comply with the primary sector's momentary, transient, and 'general' treatment procedure, where recognizing deviances from the norm are in focus and where a variety of illnesses are treated and not just one specific illness.

Everybody can agree with the idea that quality improvement, closer cooperation, and information exchange are issues that both health care sectors should strive for – it is hard to disagree on these matters. But when these intentions are operationalised we must recognise that the underlying and significant differences between the primary and secondary care sectors have a huge impact on how it should be done – differently – in the two sectors. The latter is characterised by high specialisation, epidemiological perspective, research obligations, a homogeneous patient group and related care treatments, and routine technology use. The former is characterised by a generalist perspective, personally knowing

your patients, 10–15 minutes per consultation, heterogeneity in the patient group and their care needs, and IT as a disruptive factor in the consultation. In addition to these differences related to treatment, needs, and technology usage, the general practitioners have to perceive the significant usefulness and be exceptionally motivated in order to embrace new technological infrastructures (due to their optional innovation-decision process [44]). The lesson from both cases is that the development of technological infrastructures not meeting the needs of the general practitioners as well as the needs of the secondary sector will fail. It will in the end result in an IT-supported shared care system that loses its value due to general practitioners' neglect to properly use the system.

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